

‘What seems to be the trouble?’ Stories in illness and healthcare

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Thank you for inviting me to give this lecture. It is a great honour to come from University College London to Japan and meet with your many distinguished guests. The title of my talk is “What seems to be the trouble?”. I am going to talk about stories in illness and healthcare.

I will start with this famous quote from the English philosopher Alasdair MacIntyre, who said that.



“We are never more (and sometimes less) than the co-authors of our own narratives ... We enter upon a stage which we did not design and we find ourselves part of an action that was not of our making. Each of us being a main character in his own drama plays subordinate parts in the dramas of others, and each drama constrains the others.”

In my lecture, I am going to tell you the story of a young patient called Vikram, as told by his father. Then I will talk about the defining features of stories. Next, I will consider what we might call a “good” illness narrative. Then I will talk about the role of the doctor as listener in the healing relationship. We will have some time for discussion at the end of the lecture.

I’ m going to read you a story from the Database of Individual Patient Experience, which is an online database of patients’ stories which anyone can access. The patients have consented to their stories being used in research, teaching, and even lectures like this one. I have chosen the story of a father whose little boy was diagnosed with a serious heart defect.

Here is his story.

“ Vikram was born in June, June of 2002. Normal delivery, normal, no problems. That was in June, the last week of June. And around the mid-July, it was when we for the first time we felt that he wasn't feeding very well. Now, when

we say he wasn't feeding very well, he used to take an awful long time to drink maybe 30 or 50 ml of normal milk, of SMA milk. He was on his mother's milk as well but he wasn't doing very well on his mother's milk either. He was taking a really long while to drink. We mentioned this to the health visitor and she said 'that's okay, that's something, some babies do take long'. We also didn't give it too much attention because [son's name], that's his older brother; he was a fussy eater, he was a fussy drinker and he still is. So we thought, possibly Vikram is also like that."

"But eventually it did become a problem in that he didn't get enough milk with that, in that he wasn't taking enough. We went to the GP a few times but nothing really happened. And then we also realised that he was coughing more than normal. And it wasn't a normal cough. So we mentioned this again, again they said it was something common, go away. And one other thing that we noticed at that time was that the back of his head when he was sleeping was getting all wet. Wet with sweat and his pillow was getting all wet, soggy. So we again mentioned this to the GP when we went and he said that was something that would go away. But nothing really happened."

"Then on the 23 September, that was the day he was actually diagnosed, and on that day, that morning really we noticed he was coughing very bad. And this cough was much different than the cough that he'd had all along. And it was quite bad and it was not a normal cough, really bad. So we took him to the GP and we said 'please listen to what is, see what his problem is' and then the GP said 'I hear a murmur in his heart, can you go to the hospital?' And they wanted us to go to the hospital. We went there and we were there all day and towards the end of the day they said that they suspected a hole in the heart which is the VSD."

Database of Individual Patient Experience www.dipex.org

Let's now consider the defining features of a story. In one of the great works of literary analysis, *Poetics*, the Greek philosopher Aristotle proposed that a story (narrative) has a number of defining characteristics.

The first is chronology – the time dimension of narrative. Philosopher Paul Ricoeur has emphasised the difference between calendar time (measured in days, weeks and months) and 'event time' (measured by the significant happenings in a personal story as the narrator chooses to tell it).

An interpreter told me of a consultation with the refugee mother of a 16-year-old boy who was suspected of psychosis. The psychiatrist asked “How long has he been behaving like this?” , to which the reply came “Since he saw me raped” . The mother’ s response, given in event time, provided infinitely more useful information about the boy’ s illness than one expressed in calendar time.

Trouble (such as Vikram’ s illness, or the gang-rape) is the raw material from which the plot of a story is woven.

As Jerome Bruner put it, all stories involve a tension between the canonical (that is, the normal routine of everyday life) and the unexpected. Until there is a breach from what we expect to happen, there is no story.

In the illness narrative, the focus of trouble is death, disability, disfigurement, distress, intractable pain, loss of freedom, or social stigma. The essence of the illness narrative is how health professionals, caregivers, and patients face up to these adversities.

- and this, of course, depends on their character. The villain is the person who makes trouble – or the person whose inaction makes the trouble worse.

Similarly, an autobiographical story does not merely describe the self; it creates that self. In Vikram’ s father’ s narrative of the trips to and from the primary health care team, he unconsciously portrays himself a devoted father who becomes a hero through his repeated insistence that his child must be re-examined.

One of the real joys of clinical general practice is seeing heroes being made when ordinary people tackle their illness-related troubles or step in (courageously, determinedly, and selflessly) to help others out of theirs.

The next aspect of stories I want to talk about is context. Context is the stage on which the story is enacted. Illness is the trouble that messes up our lives – but in order to understand the illness, we need also to understand the lives that are going to be messed up by the illness.

As Professor Cheryl Mattingly has put it...

“A central difficulty with clinical renderings of patient sufferings is that in their abstractness, the world of the patient is left out. This world is above all a practical and moral one in which patients have life projects and everyday concerns, things ‘at stake’ .”

Another very important dimension of stories is emplotment. Emplotment is the use of literary devices to align events and link them through the purposeful actions of

characters. Through emplotment, our heroes and villains get in and out of trouble and the narrator can show (at least implicitly) whose fault it all was.

Trouble, and the response to it, is conveyed through literary tropes such as repetition, metaphor, irony, surprise, and so on. As in Vikram's story, there is often a period of suspense in which we, the audience, do not know how bad the impact of the trouble will be.

In the Vikram story, Vikram's father uses the word 'normal' six times – to refer variously to his son's birth, his first few minutes of life, the milk he was fed, and the nature and frequency of his early cough. As the story unfolds, expressions depicting Vikram as not-ill ('normal', 'no problem', 'okay', 'common', and comparable to his not-ill brother) gradually give way to those depicting Vikram as ill ('not normal', 'really bad', 'not taking mother's milk'), until it becomes clear that a family catastrophe (the diagnosis of Vikram's major heart defect) is unavoidable.

As we read the story fragment, we are repeatedly and rhetorically pulled between 'Vikram as not-ill' and 'Vikram as ill', and in this way, the narrator conveys something of the anxiety and confusion that he and his wife felt before the definitive diagnosis was made.

Most Hollywood plots can be classified as adventure, romance, irony, or melodrama. Arthur Frank, a professor of sociology who has written movingly about his own serious illnesses, divides illness narratives into four broad genres:

restitution (in which the patient takes on the illness and gets better);
tragedy (in which the patient struggles unsuccessfully to overcome a serious illness);
quest (in which the patient embarks on a journey to find meaning and purpose in his or her incurable illness); and
chaos (in which the story is incoherent, unsatisfying, and does not make sense).

This last plot is sometimes called the 'heartsink' narrative (that is, stories by patients who make your heart sink), and I'll return to this sort of narrative in a few minutes.

So in summary, when we talk about the illness narrative, there are five things to look out for: chronology, trouble, characters, context, and emplotment. Having now defined the illness narrative, let's take it apart some more.

Doctors often ask me for a set of criteria to check whether an illness narrative is worth taking seriously! Let's take Vikram's father's narrative and see how it shapes up against the criteria that a literary critic might use to define a 'good story':

Firstly, Vikram's father's story I think has *aesthetic appeal*. The story is pleasing to hear and recount, and demonstrates a kind of internal harmony. We can all spot a good story in clinical practice. The patient who makes a minor illness into a melodrama produces less sympathy in the listener than the patient whose story is seen as genuinely touching.

Secondly, Vikram's father's story has *coherence* – that is, the succession of events and actions unfolds logically; it does not contain inherent muddles or puzzles. One aspect of coherence is what Ricoeur has called *moral order* – in other words, there is a point to the story that makes moral sense, even if the characters lack virtue and the ending is tragic.

We've all heard a 'chaos' or 'heartsink' narrative that is incoherent and deeply unsatisfying all round. There no discernible plot and it's impossible to work out which character is doing what, or for what motive. But as I'm sure you know, the heartsink narrative, by its very *lack* of coherence, tells us something important.

The third criterion for a good illness narrative is *authenticity* – the credibility of the story. This is comparable to, but not the same as, scientific validity. Perhaps we find Vikram's father's story credible because we can identify with the repeated trips made to the doctor with a sick child, trying to persuade him to take the problem seriously.

As Bruner has expressed it...

“A good story and a well-formed argument are different natural kinds. Both can be used as a means for convincing another. Yet what they convince of is fundamentally different: arguments convince of their truth, stories of their lifelikeness. The one verifies by eventual appeal to procedures for establishing formal and empirical truth. The other establishes its truth by verisimilitude.”

The next criterion for a good illness narrative is *reportability* – the 'so what' value of the story. Death is the ultimate reportable event, so stories about death (or the risk of death – as in a serious heart condition) are seen as very reportable.

Stories are told not merely to entertain the listener or convey information, but to *persuade* the listener of one's own perspective on something. The patient who brings a story of pain seeks not merely to get physical treatment, but also to formalize and legitimize their suffering through the doctor's (or nurse's) bearing witness to the story.

Laurence Kirmayer put it like this:

“People do not tell their stories in a vacuum. They must fight (be good rhetoricians or debaters) to tell their story and to have it more or less accepted, authorized, or taken up by others. They try to control the circumstances of its hearing and, to some degree, of its interpretation. But the telling is an interaction in which the audience (or interlocutor) actively shapes the telling and the teller – indeed, in which more than one (story)teller is active at once, and each shapes the other in an ongoing contest’ ”

If we move on from the aesthetic aspects of the illness narrative to more practical considerations, we can also consider how *useful* the story is in achieving particular ends for the sick person. It might, for example, have *explanatory value* – that is, it can help the patient explain and understand what is happening to them.

It might also have *diagnostic and therapeutic value* – i.e. it helps the clinician match what is happening to this patient against their medical knowledge of diseases and treatment protocols.

Finally, it might have what the therapists call *transformative value* – that is, it generates new meaning and may, for example, allow a sad, tired, hopeless or uncaring story to become a story that is more vigorous, hopeful or caring. This, of course, is the foundation on which ‘talking therapies’ of their various kinds are built.

Let’s move on now to talk about stories and the healing relationship. I’m sure you have all tried telling a story to a small child. “Once upon a time there was a king…” you might begin, and you can soon anticipate an interruption by your listener: “Was he a good king? Did he have a queen?” . Your story will not be a faithful reproduction of the text in the story book, but an *interactional narrative* between you and your listener. This is the stuff of clinical consultations, with the various interjections such as ‘uh-huh’ , ‘oh yes’ , and even ‘look here, we’ve only got seven minutes’ helping to shape the patient’s story. This principle is illustrated in the fragment from a consultation between a patient (Mrs Dunn) and her GP (Dr Patel), which is fictitious but based on a real encounter.

Patient: I’m sorry I’m late, doctor.
Doctor: Don’t worry, at least you’re here now.
Patient: I was putting my make-up on...
Doctor: Oh yes?
Patient: I looked such a mess this morning.
Doctor: A mess?

Patient: [cries]

In this short exchange, the patient says ‘I’m sorry I’m late’, and the doctor replies ‘Don’t worry, at least you’re here now’. The patient, who is encouraged by this non-judgemental response, says ‘I was putting my make-up on’, and the doctor replies ‘Oh yes’. The patient then discloses that she ‘looked a mess’ this morning and the doctor repeats this important word in a questioning manner. The patient then cries, and will soon give the doctor a story of domestic violence.

The Russian philosopher and linguist Mikhail Bakhtin, who began writing at around the time of the Russian revolution, made a key contribution to narrative theory with his claim that all text is dialogical. What he meant by this was that every utterance – even “oh yes” – is made in response to (or anticipation of) some other utterance. The audience, claimed Bakhtin, is centrally involved in creating the meaning of the stories they read or hear. Without an audience, the text has no meaning.

The doctor in this excerpt is not being passive or ‘non-directive’. He is being an active listener. He suspects that there is a story in the patient’s brief words, and by his even briefer responses he shapes the telling of that story. Imagine how different the story would have been if his first response to the patient had been ‘Please don’t be late again’.

In Bakhtin’s words...

“Human thought becomes genuine thought, that is, an idea, only under conditions of living contact with another and alien thought, a thought embodied in someone else’s voice”

In conclusion,

- 1) I have proposed a framework for studying illness as ‘trouble’ in an unfolding personal story and for studying the healing relationship as interactional narrative
- 2) The academic analysis of narrative is an interdisciplinary field of study that draws on philosophy and literary criticism.
- 3) And finally, the listener is a very important person in any narrative!

I’ll stop there, say thank you all for listening, and invite your comments and questions.